

LUPUS



LINE

Lupus Foundation Of America, Philadelphia Tri-State Chapter, Inc.

From the Chair:



It's been my distinct honor to have written in this space for over a year now. Looking back, I noticed a common theme running through each message: hope. There is little we as individuals can do to ease the pain and suffering and loss that comes with lupus, but we come together as a lupus community because of hope. Hope for a pain-free day, an encouraging visit to the doctor next week, a happy and healthy year ahead. Hope for new treatments, hope for a cure. Hope that we can provide others with comfort and support.

I lost my aunt to lupus ten years ago. Since that time, the lupus landscape has changed, and there is a lot to be hopeful for: more public awareness, more services and support, more research, more education. But two recent events left me feeling more hopeful than I can ever remember.

The first took place on October 31st, the 19th Annual Lupus Loop. What an incredible day. As the teams gathered in the early morning sun, the excitement was palpable. Each team had its own story, both sad and inspiring. One woman told me she had waited for this day for years, the day she felt good enough to walk the loop. Another told me that she walks every year despite the pain. In both cases, family and friends, with strollers and pets, many dressed for Halloween, were right by their side. And of course, many teams like mine, Team Haas, walked in memory of a loved one. One woman even pulled over on Belmont Avenue, told me she did not feel well enough to participate, and handed me a \$200 check through the window of her car. No matter the story, on that day we shared a common bond, to stand up to lupus. The numbers from the event are staggering – record attendance, \$228,000 raised. I left the Loop feeling more hopeful than ever.

The second event took place on November 16 on the University of Maryland's campus, where the FDA Arthritis Advisory Committee convened a meeting to discuss the application to approve BENLYSTA® (belimumab) as the first drug ever developed specifically for lupus. At the end of a long day of testimony from the drug's creators, other medical professionals, and lupus advocates, the Committee voted to recommend BENLYSTA for FDA approval, to a rousing ovation from a packed audience. However, the FDA has yet to approve the drug and recently delayed a final decision to March 10, 2011.

Putting the FDA decision aside for a moment, by all accounts November 16 was a magical day for the lupus community. The national LFA office convened a de-brief conference call the next day, and I listened to emotional firsthand accounts from lupus advocates who traveled from across the country to attend the meeting and, in some instances, testify before the committee. As the LFA staff members and board members from various states shared their own personal highlights, the pure happiness in their voices filled me with great hope. One person's memorable moment was listening to the testimony of a woman who admitted to the committee that BENLYSTA would *not* treat her disease-type, but spoke passionately about the need for a drug that would benefit anyone with lupus, even if it wasn't her. This selfless act moved so many people in the crowd, and it represents the best of what we can be, both as lupus advocates and as human beings. That, indeed, is reason for hope. Happy holidays to all, and here's to hoping for a better tomorrow.

Happy Holidays!

A stylized, handwritten signature of Joseph Arnold in dark ink.

Joseph Arnold
Chair



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Hortense Guggenheim Grant-in-Aid

Established by the late Hortense F. Guggenheim, this fund provides financial help for people with lupus who are unable to pay for essential medications and other lupus-related expenses. We are deeply indebted to the members of the Guggenheim Family and their friends who have sustained this philanthropic program.

If you, or someone you know, are in need of assistance, we may be able to help. Please call 215-517-5070 to request a grant application. If you would like help us sustain this fund, please use the enclosed membership application/contribution envelope.

Workplace Giving

Please remember us during your Annual Workplace Giving Campaign! You may use the following Donor Option Numbers to designate the Lupus Foundation of America, Philadelphia Tri-State Chapter as a beneficiary:

- ✓ United Way of Southeastern PA: 1071
- ✓ United Way of Delaware: 1179
- ✓ PA State Employee Combined Appeal (SECA) giving through CHC: 2000-0013
- ✓ Philadelphia School District Employees giving through United Way: 1101071
- ✓ City of Philadelphia Employees' Campaign: 14-0018
- ✓ Delaware State Employees' Charitable Campaign (SECC): 50144
- ✓ Combined Federal Campaign in greater Philadelphia: 21928
- ✓ Combined Federal Campaign in DE: 32083
- ✓ Combined Federal Campaign in Southern NJ: 21928
- ✓ If you don't see us listed in your campaign booklet, contact the Chapter Office at 215-517-5070.
- ✓ Don't forget ... many employers match contributions made by their employees to qualifying charitable organizations. Contact your personnel or community relations department for a copy of the matching gift forms. Complete this form and include it with your gift. The LFA Philadelphia Tri-State Chapter will fill in the required verification information and mail the form to the appropriate company contact.

Tributes

This year, consider making a donation in honor/memory of a loved one in lieu of a present, and we will send a beautiful acknowledgement card to the recipient(s). Your gift will be fully tax-deductible and will go towards the Lupus Foundation of America, Philadelphia Tri-State Chapter's vital mission of finding the causes of and cure for lupus, and providing support, services and hope to all people affected by lupus. We've made donating convenient by offering many choices: you may give online at www.lupustristate.org, by sending a check into our office at 500 Old York Road, Suite 110, Jenkintown, PA 19046 or by calling us at 215-517-5070.

Great Gift Ideas...

Membership

Become a member today, or sign a friend up, to show your support of the Philadelphia Tri-State Chapter! A benefit of Membership includes a subscription to Lupus Now, the nationally-ranked magazine published by the National Lupus Foundation of America. It comes packed with useful information on resources, living with lupus, medication and much more.

Gifts and contributions may be made online at
www.lupustristate.org



Stay Connected with Education and Support!

In addition to our community-based support group program, the LFA, Philadelphia Tri-State Chapter is pleased to offer:

Lupus Educational Teleconference Series Monthly Telephonic Support Group Meeting

Education and support from the comfort and privacy of your home!

Visit www.lupustristate.org or call 215-517-5070 for an updated schedule.



Riders for Amanda pictured on the Ocean City Boardwalk!

Congratulations to the Top Fundraisers for the Walk for Lupus Now in South Jersey!

Individuals:

Christopher Pinto	\$1,225
Kristin Carr	\$1,050
Maria Widmeier	\$615

Teams:

Nicole's Lucky 7	\$6,450
The "K" Team	\$2,910
Sherrishine	\$2,252

Walk for Lupus Now Events Grow!

Earlier this year, 750 supporters participated in our 2nd Annual *Walk for Lupus Now* events held in Ocean City, NJ and Wilmington, DE. Both boardwalks were filled with hundreds of walkers, volunteers and other supporters, joining the Lupus Foundation of America in the fight against lupus. Together, the 2nd Annual *Walk for Lupus Now* events have raised nearly \$47,000 to support programs of awareness, education and community services in Delaware and Southern New Jersey! We want to thank all those who fundraised, donated and walked! Give yourselves a round of applause!

We would like to also thank the City of Ocean City, NJ, the Wilmington Riverfront Corporation, Convey2Web, Tonbo-Visual Promotions, Wilmington Metropolitan Urban League Nu-Lites Program, Best Buy and Blue Cross/ Blue Shield for their dedication and support of the 2nd Annual *Walk for Lupus Now*. We also would like to send a special thank you to WMGM-TV 40, the local NBC Affiliate in Atlantic City for their news piece about lupus and *Walk for Lupus Now*! It was truly a team effort by all!

Save the dates for the 3rd Annual *Walk for Lupus Now* events:

- May 15, 2011 in Ocean City, NJ
- June 5, 2011 in Wilmington, DE

With your help and efforts, we will continue to grow the *Walk for Lupus Now* events to support those living with lupus. Together we will fight lupus one step at a time!

If you are interested in volunteering (individual or group) or for information on sponsorship opportunities, contact Christopher Waters, Community Development Manager at (302) 622-8700 or cwaters@lupustristate.org.



Congratulations to the Top Fundraisers for the Walk for Lupus Now in Delaware!

Individuals:

Noreen Ruczhak	\$600
Lindsay Schulze	\$553
Colleen Ziegler	\$370

Teams:

Brockenbrough and Wilkins	\$3,587
Tish's Team	\$2,275
Team Anouska	\$1,202



Andrew Marshall is "In Motion for Melody"



Team Lively Lupies takes a rest!



Members of Team Tonii enjoy the view!



MEMORIALS AND TRIBUTES

Our Officers and Board Members extend heartfelt sympathy to the loved ones of those whose names follow, and in whose memory we received thoughtful gifts. We also thank all making donations in honor of friends and loved ones. These Memorials and Tributes were received during the months of September-November 2010.

IN MEMORY OF

BONNIE JEAN BROWN
Barbara & Bob Baumann
Tracy & Bob Baumann
Irene M. Thomas
Suzanne & Fred Weber

HELEN EICHENBAUM
Lana Grossberg

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Nancy Berger

PATRICIA BORN
Your Birthday
Nancy Berger

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Happy Birthday
Jon, Harriett & Brett
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Our Best Wishes
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DR. ARLYNE SHOCKMAN
A Successful Bridge Tournament
Mr. & Mrs. Sigmund Hoffman

BUNNY STEINGARD
A Speedy Recovery
Renee & Mike Samson

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Members who enrolled in previous months were listed in the newsletter for that quarter.

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Catherine Diimmier

Special Update on Potential New Treatment for Lupus

On November 16, 2010, the U.S. Food and Drug Administration (FDA) Arthritis Advisory Committee voted overwhelmingly (13 to 2) to recommend BENLYSTA® for approval as a treatment for the autoimmune disease lupus. Subsequently, FDA officials announced a final decision regarding approval has been delayed until March 10, 2011.

Sandra C. Raymond, President and Chief Executive Officer of the national Lupus Foundation of America (LFA) has issued the following statement:

"We are pleased that BENLYSTA has cleared a significant hurdle on its path to becoming the first FDA-approved medication for lupus in 52 years – since Dwight D. Eisenhower was president. BENLYSTA is now on track to become the first approved treatment ever developed specifically for lupus.

The recommendation by the FDA Advisory Committee is not only a victory for developers Human Genome Sciences and GlaxoSmithKline, but also for the entire lupus research community and industry. We have all worked for decades to overcome many challenges in developing new therapies for this unique and difficult-to-treat disease. For people with lupus, the panel's recommendation represents a beacon of hope that new and improved treatments can be specifically developed for lupus.

It is important to understand that a delayed decision from the FDA does not indicate whether they will approve or reject BENLYSTA. We appreciate the efforts of the FDA to ensure that medications for people with lupus are safe, effective, and tolerable."

Annette Myarick, CEO of the Philadelphia Tri-State Chapter attended the November 16th hearing with Board Member Dr. Laura McCloskey. Myarick said, "The testimony given by the individuals affected by lupus was very powerful and demonstrated well the urgent need to develop new, safe, effective, and tolerable treatments for lupus." Each person with lupus is unique, and if BENLYSTA is approved, it would be a significant and necessary first step towards creating the full arsenal of treatments that lupus requires.

The LFA thanks the committee and FDA officials for their time and review to ensure the safety and efficacy of this potential medication for people with lupus. We also want to thank the numerous individuals with lupus and their families, who provided testimony and attended the hearing to show their support.

We are greatly encouraged by the panel's vote, and eagerly await the FDA's final decision. The LFA will continue to follow this process closely, and keep constituents apprised of developments.



Winter Checklist: 5 Small Steps to Stay Healthier

Holiday card list drafted? Check. Small gifts purchased for the kids' teachers? Check. Prevention plan to stay healthy this winter? Ch...wait, was that on my "to do" list?

As you prepare for the holiday season and the cold winter months, be sure to consider what small steps you can take to try to prevent catching a cold or the flu. Here is a winter weather checklist aimed at staying healthy this season.

1. Get a flu shot.

Flu shots are safe and do not increase lupus disease activity. This year, the H1N1 vaccine will be a part of the regular flu shot, so one shot will offer protection. People with lupus and those who live with a person with lupus should not use the FluMist® nasal spray because it contains a live form of the flu virus. For more about the dangers of H1N1, read one woman's story online at lupus.org/H1N1.

2. Wash your hands frequently.

Many people underestimate the time it takes to clean their hands properly. You should scrub your hands with warm running water and soap for 15–30 seconds. Sing "Happy Birthday" to yourself twice while washing. And don't forget to scrub your wrists, fingernails, and the backs of your hands.

3. Don't shake hands.

Wouldn't it be great if Americans did away with the disease-spreading handshake greeting? Perhaps we should bow, as they do in Japan, or simply raise our hand in a warm welcome. Until then, you can keep your hands full—at holiday parties, make sure you always have a glass in your hand. Or, a simple nod and "nice to meet you" will suffice.

4. Disinfect shared items at the office.

Shared handles at work can help spread germs around the workplace. Keep sanitizing wipes at your desk to wipe down your telephone receiver, keyboard and mouse, doorknobs, and microwave handles. Avoid touching water fountain handles, faucets, and elevator buttons with your fingers. Instead, use your sleeve, glove, or a paper towel.

5. Wear sun block in winter.

Exposure to ultraviolet (UV) light, both indoors and from the sun, can increase lupus activity. UV light can still come through the winter clouds. To help prevent your skin from drying out, start with a winter moisturizer that contains SPF of 15 or more. Apply your regular sunscreen generously and in addition to your regular skin care routine.

LUPUS LINE WINTER 2010-2011

Lupus Line is a publication of the Lupus Foundation of America (LFA), Philadelphia Tri-State Chapter, Inc. If you have any questions or comments, please feel free to call the office at 215-517-5070. Or you can write to us at:

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Join Us for Advocacy Day!

March 1, 2011

Lupus Advocates from PA, NJ and DE are needed to travel to Washington, DC to meet with legislators and urge them to increase funding for lupus research and programs.

Please join us! For more information or to reserve a seat on the bus contact the chapter office at 215-517-5070 or info@lupustristate.org

